

# A 'Magic Pudding' Dilemma

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I would like to acknowledge the Traditional Owners of the lands on which we are gathered – and pay my respects to their Elders, past, present, and emerging.

Where it all began...

It is wonderful to be back in Newcastle – the lands of the Awabakal and Worimi peoples.

It's wonderful because this is where the National Disability Insurance Scheme began.

This is where the Australian people started the work that has changed the trajectory of the lives of hundreds of thousands of their fellow citizens.

This is where people with disability, families, carers, and disability service providers came together standing on the shoulders of those who came before us ...

.. and commenced a new, generational effort to make the Australian way of life more accessible and inclusive for people with disability.

This is where then-Prime Minister Kevin Rudd came – on July 1, 2013 – to kick-off the national rollout of the NDIS.

**This** is the place. Right here.

It's easy to forget how far we're come since July 2013.

In a decade, disability has gone from an issue on the margins to one of the core policy areas for Commonwealth, State and Territory Governments.

In that time,

The NDIS has gone from a grassroots idea born outside Canberra to a portfolio with its own Cabinet Minister;

It has gone from zero to more than 600,000 participants;

And the lives of those Australians and their families have been forever and overwhelmingly changed for the better.

There is **nothing** like the NDIS anywhere else in the world.

It **is** unique.

It **is** changing for the better the lives of hundreds of thousands of people with disability.

And the best is yet to come.

We are yet to see the full payoff from our investment in the NDIS ...

.. because the national roll out of the Scheme began in July 2013 and only finished in July 2020.

That means we're barely three years into an investment designed to deliver social and economic benefits over the lifetime of a participant.

And to the broader Australian community.

Of course, this generation of adults with disabilities are already benefiting from the NDIS ...

.. but those benefits will be multiplied when this generation of children with disabilities reach adulthood.

Such is the nature of generational reform: there is a time lag between the investment and the payoff.

Right now, we're in a time lag.

Individually, the NDIS **is** opening doors for people with disability and their families and is making our country stronger and fairer – but, nationally, the magnitude of those benefits are yet to be seen.

That is why, in the meantime, we share a responsibility.

The NDIS is a policy miracle. And we have a responsibility to protect that miracle, maximise its impact and make sure it works for generations to come.

All of which begs a series of questions:

Where **is** the NDIS going? Are we happy with its direction? Or do we need to change?

I've asked those questions a hundred different ways since the NDIS Minister, Bill Shorten, asked me to co-chair the NDIS Panel with Lisa Paul.

And I have not liked all the answers I've found.

And that is what I want to talk to you about today.

Since the NDIS Review began last October, the Independent Review Panel members have visited every State and Territory multiple times.

We have engaged directly with people with disability, families, carers, and service providers.

We have travelled from Darwin to Alice Springs via Maningrida, Groote Eylandt, Tennant Creek and Ali Curung – where the NDIS commenced in the Northern Territory eight years ago.

We have met with many thousands of people.

And we have received more than 2,500 submissions from participants, their families and those that support them which contain rich experience and thoughtful feedback.

The most significant thing we've heard is how the NDIS has transformed hundreds of thousands of lives.

We've heard about people getting the supports they need for the first time, and how the NDIS has helped them develop new skills and get jobs or volunteer.

We have also heard about parents being able to re-join the workforce and rebuild careers.

However, at the same time we have heard how the NDIS has caused stress and fear.

We have heard that not everyone who needs the NDIS is getting the help they need.

We have seen and heard how, in some cases, the NDIS has **not** driven inclusion but, instead, has driven segregation.

And we have seen how the NDIS market and competition are **not** delivering for people with disability and, in the worst cases, are leading to abuse and exploitation.

At the end of June, we put all that we had seen and heard and learned into a report entitled *What we have heard*.

We could not have written that report with all its insights without you.

I want to thank everyone for your deep engagement with and support for the Review.

Thank you for your trust, confidence and ideas.

We have taken your insights and come up with five key challenges we think the NDIS faces:

It is an oasis in the desert for people with disability.

It's fundamental purpose – delivering reasonable and necessary supports – has become unbounded and, therefore, some service demands and types are increasingly unreasonable and/or unnecessary.

It supports far more children than projected.

Its markets are not working, and

As a consequence, its sustainability is being questioned.

Most of these challenges were already known.

They have been identified many times – going back to the Productivity Commission Report on NDIS Costs in 2017, numerous Joint Standing Committee reports and the Tune Review.

Yet not much of significance changed.

Knowing all that, the Panel has come to two major conclusions.

Our first conclusion is that the NDIS is, as I said, uniquely Australian – and a policy miracle.

Against the odds, it came into being.

Against the odds, it survived.

Against the odds, it changed for the better the lives of hundreds of thousands of Australians.

It is one of the great achievements of our Federation – and a breathtaking demonstration of the decency and fairness of the Australian people.

Our second conclusion is more sobering: to protect the miracle that is the NDIS we must commit to real and enduring change.

Let me repeat myself: **real change**.

Not marginal change. A real change to the operation of the NDIS and the ecosystem of supports and services that are supposed to complement it.

I realise that this statement will raise hopes and fears.

Hopes that the NDIS will change for the better;

Fears that, after a decade of disruption, we face more change.

Speaking as a parent, I understand both sentiments – especially the fear – but, believe me, change is necessary.

Real change is necessary because, based on what you have told us, the NDIS is not working for everyone.

It is too inequitable – over-delivering for some, underdelivering for many, and not delivering at all for the majority of Australians with disability.

What is even more worrying than the inequity is the air of unreality that exists around the NDIS.

Let me put it this way: we must stop thinking of the NDIS as though it is a limitless Magic Pudding.

What has become clear is that – often without intending to – governments, service providers, and some people with disability and their families, have **all** started to treat the NDIS as a limitless resource.

Ironically, governments – while funding the NDIS and worrying about its increasing costs – keep helping themselves to new slices of the NDIS.

Rather than, in an era of tight budgets, delivering universally-accessible services – in areas such as health, early childhood, education, housing, and transport – governments often expect the NDIS to do more.

Disability service providers also want more – not to mention the examples of fraud and unethical practices.

Meanwhile, packages for many participants keep growing.

Some packages increase due to changed circumstances. Some due to a lack of clarity about what is reasonable and necessary. And some because participants are worried about losing the support they rely on.

As I said, we have **all** started to treat the NDIS as a magic pudding.

But the NDIS is not limitless – and we **all** need to stay within the bounds of those limits.

That is why we need to change.

We all have a part to play in these changes – participants, families, providers and governments.

The Review is speaking to governments. And I will be speaking to providers later this afternoon.

This morning, though, I want to explain what these changes mean for people with disability, their families and carers.

Let me begin by discussing the NDIS's 'oasis in the desert' problem.

### *Challenge 1: Oasis in the Desert*

In its 2011 report, the Productivity Commission envisaged the NDIS working in tiers.

Tier 1 covered all Australians.

Tier 2 covered people with disability who do not need an individualised support package – roughly 1-in-5 Australians.

Tier 3 covered people with permanent and significant disabilities who required individualised support – roughly 1-in-50 Australians.

All governments, through Australia's Disability Strategy or ADS, promised to create 'inclusive and accessible communities' for the 1-in-5 Australians with disability.

That meant mainstream services – such as early childhood, health, education and housing – would become accessible to all Australians with disability.

But that promise was only backed with insufficient funding – and, as a consequence, many mainstream services remain unavailable or inaccessible.

We've also seen the **loss** of general disability supports and **cuts** to long-term funding for mission-driven disability organisations ...

.. as well as the sidelining of the Information Linkages and Capacity Building program and Local Area Coordinators – both of which were meant to build community capacity and community supports.

That means, if you are a person with a disability without an individualised package, you are effectively on your own.

No wonder the NDIS is under immense pressure.

In response, the Review is considering two key recommendations.

First, we are considering abolishing the Tier 1, 2, 3 approach envisaged by the Productivity Commission ...

.. because that approach prioritises the delivery of individualised support to the **minority** of people with disability who are NDIS participants.

That focus on implementing individualised funding made sense during the rollout of the NDIS.

Now that the NDIS is rolled out, we believe there is a need to prioritise the delivery of universal or foundational supports to the **majority** of people with disability and to create a joined up system rather than one which is divided into tiers.

Foundational supports available for **all** Australians with disability would include such things as information and peer support. And for a smaller number of people there would be supports such as assistance with shopping, cooking, and cleaning.

In addition, we want to see much better support for children with emerging developmental concerns and delay through maternal and child welfare centres, integrated child and family centres, and early childhood education.

Individualised supports – through the NDIS – should be built in a graduated way on top of those foundational supports – creating a far more equitable and sustainable system.

In order to give confidence to the disability community and to reinforce the links between the Australian Disability Strategy, the NDIS and a commitment to delivering foundational supports, the Panel believes that there should be a single inter-governmental agreement drawing these policies together – and, if needed, holding governments to account.

#### *Challenge 2: Clarifying reasonable and necessary*

The second challenge you helped us identify is the need to clarify what is meant by ‘reasonable and necessary supports’.

At times, reasonable and necessary has been interpreted very differently by the NDIA without any changes in the legislation, rules, or operating guidelines.

In addition, decisions on supports have been unfair and inconsistent – with some participants receiving much more support than other participants with similar needs.

What you’ve told us is that you want fairness, transparency, and certainty around the definition of ‘reasonable and necessary supports’.

The Panel agrees on the need for greater fairness, transparency, and certainty.

That’s why we are considering three important changes.

First, we’re considering how budgets are put together for participants.

Currently, those budgets are constructed line-by-line, item by item - leading to endless arguments and lots of wasted time and money providing reports.

This was never the intention of the NDIS.

It was designed to provide an overall budget that is ‘reasonable and necessary’ then give participants control and choice over how they spend their budget.

The combination of line-by-line planning and participant demands for control and choice have blurred the definition of ‘reasonable and necessary supports’.

It's not producing a good experience for participants – or good outcomes. And it is contributing to financial pressure on the NDIS.

The Panel's emerging view is that 'reasonable and necessary supports' should be set at an overall package level rather than line-by-line.

The second change we are considering is how 'reasonable and necessary supports' are decided.

Currently, the process of determining 'reasonable and necessary supports' start with assessing functional impairments.

This medical approach misses the point of the NDIS – which is to deliver people with disabilities the supports they need to undertake daily activities and participate in the community.

Funding should therefore be determined by the supports people need to actively participate in the community, their goals as well as their environment – things like their living arrangements should all be taken into account.

The third change we are considering is whether – rather than being outsourced to Local Area Coordinators – the National Disability Insurance Agency should determine what is reasonable and necessary.

Under this approach, the Agency would also be responsible for commissioning – and paying for – expert reports when needed.

Of course, this change would have flow-on effects for the NDIA in terms of skills, experience, staffing and culture.

That is why I am glad there has been a down payment on increasing the capacity of the Agency's workforce in the recent Budget.

Finally, the Panel's emerging view is that combining planning and budget setting contributes to the stressful relationship between participants and their families and the NDIA.

That's why the Panel is considering whether planning should occur after participant budgets are determined.

We think that this change would be a less stressful experience and give participants more help and flexibility in using their funding to meet their needs.

### *Challenge 3: Early childhood*

A third challenge relates to early childhood.

This is an area that needs a complete and urgent rethink.

First, based on the Nationally Consistently Collected Dataset, 20 per cent of children experience learning difficulties, developmental concerns, developmental delay or are found to have disabilities.

In other words, learning difficulties and disability are mainstream issues.

This is why we are emphasising the needs of children, as part of our proposed reforms to foundational supports.

Second, we want children with developmental concerns and delays to be identified as early as possible in mainstream settings through vaccinations and other check-ups.

Third, early intervention needs to be based on best-practice evidence and principles; needs to be built around a key worker; and – unless there is a need for clinical intervention – needs to be delivered mainly in homes, early childhood settings and schools.

We want children and their families to have **every** opportunity to lead ordinary lives included in their local communities.

Finally, the Panel is of the view that there also needs to be much better support for families.

In conclusion, let me leave you with three thoughts.

First, progress has – and is – being made.

The last Federal Budget made significant investments to build the capacity of the NDIA as well as prevent fraud.

In addition, the number of appeals to the Administrative Appeals Tribunal have been significantly cut and hospital discharge rates have been significantly improved.

And, for the first time, 50 per cent of the members of the NDIA Board are people with disability.

The challenge ahead of us is to keep pushing for progress.

Second, I deeply understand, that every person with disability, their families and carers crave certainty. As a result, any changes that flow from this Review must be carefully staged and clearly communicated.

Careful and effective implementation and monitoring which centres the voices of people with disability and their families will be essential.

Third, and this is the more profound point, the NDIS does not belong solely to us.

Yes, we fought for it. Yes, we protected it. Yes, we depend on it.

But the NDIS does not just belong to us. It also belongs to the generations that follow us.

We are all – and by that I mean people with disability, families, carers, providers – custodians of the NDIS.

With rights come responsibilities and we have a responsibility – if we want to live up to our promise to make every Australian count – to maximise the social and economic benefits of the miracle that is the NDIS.

Every person with disability, every family member, every carer, every service provider and all governments have a role to play in this change.

It was a united disability sector which gave Australia the NDIS.

Now, more than ever, we need to remain united and determined.

Then and only then will the future of the NDIS be secure in a form which matches our hopes and dreams of a decade ago.